

Early Intervention for Deaf and Hard of Hearing Children and their Families STAKEHOLDERS MEETING

Agenda

8:30	-	9:00	Registration	
9:00	-	9:30	Welcome & Introductions	Brenda Fink, Yasmina Bouraoui
9:30	-	10:00	Vision Statement	Nancy Peeler, Michelle Garcia, and Kylie Sharp
10:00	-	10:15	Introduce Arlene	Vanessa Winborne
10:15	-	10:45	System Attributes	Arlene Stredler-Brown
10:45	-	11:00	Break	
11:00	-	11:30	System Attributes, cont.	Arlene Stredler-Brown
11:30	-	11:45	Revisit Vision	Nancy Peeler, Michelle Garcia, and Kylie Sharp
11:45	-	12:00	Break	
12:00	-	1:00	Lunch	
1:00	-	1:45	Overview of Colorado Model	Arlene Stredler-Brown
1:45	-	2:15	Current Michigan Services	Arlene Stredler-Brown
2:15	-	2:30	Report Out on Services	Nancy Peeler
2:30	-	2:45	Next Steps	Yasmina Bouraoui
2:45	-	3:00	Wrap Up	Yasmina Bouraoui

**Early Intervention for Deaf and
Hard of Hearing Children and their Families
Stakeholder's Meeting
March 28, 2006**

Background

- A number of systemic issues around services for Deaf and Hard of Hearing children between ages 0-5 have been identified and there is a growing momentum to address these issues. The Michigan Department of Community Health and the Department of Education have joined forces to address these concerns.
- Research has shown that early identification of hearing loss, when followed by immediate intervention, provides the potential that children with hearing loss can develop communication and language skills commensurate with their hearing peers.
- Currently there is wide disparity in information and materials being provided for parents by numerous professionals with whom a parent has contact after the child's confirmation of hearing loss. There is no specific entity or one professional designated to provide information in Michigan. Every family with a deaf or hard of hearing child should have access to high quality services for both the parents and the child. Michigan children are falling through the cracks in the current system. For example in 2004, while 94 % of children were screened as newborns, with a referral rate of 3.5%, only 54% are reported to receive a diagnostic evaluation, and only 39 % of those with a diagnostic are reported to enroll in and receive early intervention services. It is unknown how many D/HH children in Michigan eventually succeed in developing communication and language skills commensurate with their hearing peers.
- There are poor connections across the programs that constitute the current service system, which contributes to the lack of continuity of care. (e.g. lack of data collection, lack of procedure/policy to ensure quality and continuity in screening and early identification of hearing/vision status, separate data systems that prevent data sharing and collaboration).
- Families report a lack of information about availability of services and funding sources to implement services/access needed resources and technology.
- Michigan's current service system tends to reflect a medical model rather than a service delivery system that is family-centered and culturally appropriate. Families and professionals alike have expressed concerns about our current system's ability to provide a full range of appropriate services, including both medical and cultural interventions, after identification of a hearing loss.

Purpose

To identify and implement a results-based approach to achieve the design/redesign of Michigan's continuum of care system for children 0-5 who are Deaf and Hard of Hearing and their families. It is recognized that many communication options are available to facilitate the development of language milestones that are commensurate with those of hearing children. The intent of this work group is not to discuss the merits of one mode of communication over the other but to recognize the need to inform parents of all options, and to develop access to a broad range of services.

Goal

The work group's primary goal is to provide recommendations from a variety of stakeholders to improve the continuum of care for children 0-5 who are Deaf and Hard of Hearing. It will achieve this through two activities: 1) Informing parents of all early intervention services, and 2) developing reasonable access to a broad range of high quality services for families.

Anticipated Outcomes

- Acknowledgement of the vision statement to address a model system of care for early intervention services
- Identify the core components of the model system
- Identify the core set of early intervention services needed in Michigan to reach the model system

Early Intervention for Deaf and Hard of Hearing Children and their Families

Stakeholder's Meeting

March 28, 2006

Housekeeping issues:

- Please turn your cell phones on silent or vibrate
- An agenda is included in your packet.
- We will have a break at 10:45 and break for lunch at 11:45. We will need to vacate the room at that time so they can set up for lunch.
- Evaluation forms are included in your packet. Please be sure to turn them in at the end of the day at the registration desk.

Communication Etiquette

- One person communicates at a time.

Communication Etiquette

- Please leave the room to communicate privately with another individual.
- Please use any microphones which are provided.

Communication Etiquette

- During review of distributed documents, please withhold comments until everyone has finished reading .
- When voting on issues, we will vote visually by raising our hands.

Communication Etiquette

- Thank you for being sensitive to all forms of communication.

(Communication Etiquette taken from the Michigan Coalition of Deaf and Hard of Hearing people.)



Why are we here?

Why are we here?

- Systemic issues around services for Deaf and Hard of Hearing children between ages 0-5 have been identified
- The Michigan Department of Community Health and the Department of Education have joined forces address these concerns

Why are we here?

- Early identification of hearing loss, when followed by immediate intervention, provides the potential that children with hearing loss can develop communication and language skills commensurate with their hearing peers.

Why are we here?

- Wide disparity in information and materials being provided for parents
- No specific entity or professional is designated to provide information in Michigan.

Why are we here?

- Poor connections across the programs that constitute the current service system, which contributes to the lack of continuity of care.

Why are we here?

- Families report a lack of information about availability of services and funding sources to implement services/access needed resources and technology

Why are we here?

- Current service system tends to reflect a medical model rather than a service delivery system that is family-centered and culturally appropriate.
- Current system's inability to provide a full range of appropriate services

**Centers for Disease Control
(CDC) National Goals, Program
Objectives, and Performance
Measures
for
Early Hearing Detection and
Intervention (EHDI)**

CDC EHDI National Goals

1. All newborns will be screened for hearing loss before 1 month of age, preferably before hospital discharge
2. All infants who screen positive will have a diagnostic audiologic evaluation before 3 months of age
3. All infants identified with hearing loss will receive appropriate early intervention services before 6 months of age (medical, audiologic, and early intervention).

CDC EHDI National Goals

4. All infants and children with late onset, progressive, or acquired hearing loss will be identified at the earliest possible time
5. All infants with hearing loss will have a medical home as defined by the American Academy of Pediatrics
6. Every state will have a complete EHDI Tracking and Surveillance System that will minimize loss to follow-up
7. **Every state will have a comprehensive system that monitors and evaluates the progress towards the EHDI Goals and Objectives**

3.2 Early intervention services

Each state will ensure that all infants and children with documented hearing loss will receive appropriate early intervention services from Part C or other state approved intervention services.

Service coordination will be provided to eligible children

CDC EHDI National Goals 3.2

- a. Number and percent of infants with hearing loss who were enrolled in an intervention program before 6 months of age
- b. Number and percent of infants and children with hearing loss who received family support information about early intervention services.
- c. Number and percent of eligible infants and children categorized by hearing loss who have a signed IFSP or an equivalent intervention plan.

CDC EHDI National Goals 3.2

- d. Number and percent of infants who are lost to follow-up after identification.
- e. Number and percent of infants with hearing loss eligible for Part C services with mild hearing loss, moderate hearing loss; moderately-severe hearing loss, severe hearing loss, or profound hearing loss.

3.3 Audiologic services

All infants identified with hearing loss will receive appropriate audiologic services before 6 months of age

CDC EHDI National Goals 3.3

- a. Documentation that confirms that families of children with hearing loss received information on communication and amplification options.
- b. Documentation of plan for management of each infant's and child's assistive technology that includes, at a minimum use of probe microphone measures and recommendations for frequency of evaluation.

CDC EHDI National Goals 3.3

- c. Documentation of protocols and guidelines for managing the aural habilitation or rehabilitation of each infant or child.
- d. Number and percent of infants fitted with personal amplification before 6 months of age

3.4 Policy statement for stakeholders

Each state will adopt and distribute as appropriate a policy regarding the rights of every family to choose the communication modes and methods that are most appropriate for their child.

CDC EHDI National Goals 3.4

- a. Documentation of procedural safeguards regarding the rights of families when choosing a communication mode for their children.
- b. List of resources and contacts providing information about various communication options to enable families to make more informed decisions.

CDC EHDI National Goals 3.4

- c. Documented plans for distributing the resource list and procedural safeguards to families identified by the newborn hearing screening program.

3.6 Membership of IFSP or other intervention team

All families who have a child with identified hearing loss should have an individual on their intervention team who has knowledge, experience, and expertise with the issues related to children who are deaf or hard of hearing.

CDC EHDI National Goals 3.6

- a. Number and percent of intervention teams that include individuals with professional preparation and experience working with children with hearing loss.

3.9 Recommendations for early intervention providers

States shall develop a set of recommendations for early intervention providers who work with children who are deaf or hard of hearing and their families that include:

3.9 Recommendations for early intervention providers (cont'd)

- identification of objective sources of information for families to learn about communication options,
- guidelines for monitoring the communication and social skill development of the child with hearing loss at 6-month intervals
- identification by each early intervention program of personnel within their staffs who are specialists in deaf and hard of hearing issues

3.9 Recommendations for early intervention providers (cont'd)

- process for linking to family-to-family support within an early intervention system,
- list of preschool program options that are particularly prepared to serve children who are deaf or hard of hearing,
- inclusion of this information in the preparation of the family for transition at age 3 years.

3.9 Recommendations for early intervention providers (cont'd)

- a. Documented distributions of a resource guide that presents balanced information on communication options
- b. Documented test scores for communication and social skill development at 6-month intervals.
- c. Documentation of annual updated guidelines.
- d. Number and percent of families referred to and involved in parent-to-parent support program.

3.6 Membership of IFSP or other intervention team

All families who have a child with identified hearing loss should have an individual on their intervention team who has knowledge, experience, and expertise with the issues related to children who are deaf or hard of hearing.

6.1 Comprehensive system

Each state will have a computerized system that maintains current information on hearing screening for every infant, evaluation for all infants and children who do not pass the screening and interventions for every infant and child from birth through 5 years of age with hearing loss.

7.0 Every state will have a comprehensive system that monitors and evaluates the progress towards the EHDI Goals and Objectives

7.4 Surveillance of follow-up services.

Each state will ensure that infants and children with hearing loss receive ongoing and appropriate follow-up services.

- b. Number and age of infants and children fitted with implants.
- c. Number and percent of infants and children using each mode of communication, e.g., sign language, oral, cued speech at 6-month intervals.

7.4 Surveillance of follow-up services.

Each state will ensure that infants and children with hearing loss receive ongoing and appropriate follow-up services.

- d. Number and percent of infants and children achieving communication and social skills scores commensurate with their cognitive abilities age at 1, 3, 5, and 7 years of age.
- e. Number and percent of infants and children with hearing aids that receive follow-up visits at 2-month intervals until age 2 years and 3-month intervals until age 3.

Quotes from parents...

- “I wish I would have been educated on the different services available to my family in the State of Michigan “

Quotes from parents...

- “The communication choice I have made for my Deaf child is not available to us anywhere in the State of Michigan “

Quotes from parents...

- “My son's baby nurse in the newborn delivery room cried when he “failed” the hearing screening. My husband and I had to console her and tell her that we were okay with it. The nurse said “But it's a hearing world”. To me - that was like saying “But it's a white world”, or “But it's a man's world”” “

Quotes from parents...

- “Real information, support and high expectation are what true intervention is “

Quotes from parents...

- “We contacted Early On for intervention services in sign language. We were told the only early intervention option in our county was oral. They didn't have anyone on staff that could sign “

Quotes from parents...

- “ The best speech therapist that came to our home was the one who didn't come with her own agenda, rather, she looked around at our family, our home and used what we had to help encourage our son's speech development “

Quotes from parents...

- “We were limited for choices because of where we lived. I had to move my family in order to receive satisfactory programs “

Purpose of Stakeholder Meeting

- To identify and implement a results-based approach to achieve the design/redesign of Michigan's continuum of care system for children 0-5 who are Deaf and Hard of Hearing and their families.

Purpose

- To recognize the need to inform parents of all communication options, and to develop access to a broad range of services.

Goal:

- To provide recommendations to improve the continuum of care for children 0-5 who are Deaf and Hard of Hearing through:
 - ◆ 1) Informing parents of all early intervention services
 - ◆ 2) Developing reasonable access to a broad range of high quality services for families

Anticipated Outcomes:

- Acknowledgement of the vision statement to address a model system of care for early intervention services

Anticipated Outcomes:

- Identify the core components of the model system

Anticipated Outcomes:

- Identify the core set of early intervention services needed in Michigan to reach the model system

Workgroups:

- Policy
- Funding
- Practice

**“When it comes to the future,
there are three kinds of people:
those who let it happen, those who
make it happen, and those who
wonder what happened.”**

John M. Richardson, Jr.

National Goals, Program Objectives, and Performance Measures for the Early Hearing Detection and Intervention (EHDI) Tracking and Surveillance System

In collaboration with state participants and representatives from other federal and national agencies, CDC developed EHDI program objectives and performance indicators. Numerous sources were used to identify these objectives and indicators, such as state guidelines and the position statements of the Joint Committee on Infant Hearing (JCIH) and the American Academy of Pediatrics (AAP). States are responsible for putting these objectives into a feasible time line.

Goal 1. All newborns will be screened for hearing loss before 1 month of age, preferably before hospital discharge.

Program Objectives	Performance Indicators
1.1 <i>Universal screening.</i> All birthing facilities will have a universal newborn and infant hearing screening (UNHS) program that screens all newborns. Small hospitals that do not screen newborns will refer infants to a screening program.	<ul style="list-style-type: none"> a. Number and percent of birthing hospitals in the state that screen at least 98% of infants before discharge. b. Number and percent of small hospitals that do not screen but have plans for referral of infants to a screening program, including designation of responsible staff positions(s) and timeline. c. Number and percent of infants screened before hospital discharge. d. Number and percent of infants screened before 1 month of age. e. Number and percent of infants whose families refuse screening.
1.2 <i>Information on newborn hearing and the screening process.</i> All birthing facilities will have linguistically appropriate and culturally sensitive brochures or other materials to inform parent(s) or guardians of newborns about the newborn hearing and screening process before the infant is screened.	<ul style="list-style-type: none"> a. Number and percent of pregnant women that received EHDI information before delivery. b. Number and percent of new parents that receive EHDI information in the hospital at the time of delivery. c. Number and percent of hospitals that provide information packets in Spanish, or other languages spoken by at least 5% of the population.
1.3 <i>Demographic data.</i> All hospitals will collect demographic data such as race/ethnicity, educational level of the mother, and type of insurance covered before hospital discharge.	<ul style="list-style-type: none"> a. Number and percent of infants in each racial/ethnic group. b. Percent of infants whose mothers are in each category of level of education. c. Number and percent of mothers in each insurance category.

1.4 <i>Out of hospital births.</i> States will have a mechanism to ensure that infants not born in birthing hospitals will receive a hearing screening.	a. Number and percent of infants born out of hospital. b. Number and percent of infants born out of the hospital that received a hearing screening before one month of age.
1.5 <i>Financial barriers.</i> Each state will develop a system to reduce/eliminate financial barriers to newborn hearing screening.	a. Published guidelines to reduce financial barriers that include information for parents on how to receive financial help or free screening and/or diagnostic services. b. Number of hospitals or other relevant organizations to which the guidelines were distributed, including designation of responsible staff and timelines.
1.6 <i>Reporting.</i> Results of the hearing screening will be provided to the infant's parents and primary care provider (PCP).	a. Forms and stated protocol for providing screening results to parents and PCP are available.
1.7 <i>Linkage and referral to audiologic follow-up.</i> Each state will identify a linkage system to ensure that all infants who do not pass the hearing screening will have appropriate referral for diagnostic evaluation.	a. Number and percent of infants that do not pass the initial inpatient or outpatient screening and are referred for diagnostic audiologic evaluation.
1.8 <i>Education and training.</i> Hospitals or EHDI program will have a training plan for all service providers, including screeners (inpatient and outpatient), nurses, and physicians.	a. Yearly or semiannual list of training sessions completed (or planned) for screeners, nurses, and physicians.
1.9 <i>Screening protocols.</i> Hospitals will have written hearing screening protocols that include standard policies, procedures for screening, and appropriate forms.	a. Copy of hearing screening protocols.

Goal 2. All infants who screen positive will have a diagnostic audiologic evaluation before 3 months of age.

Program Objectives	Performance Indicators
2.1 <i>Audiologic evaluation.</i> Audiologists will administer a comprehensive audiologic evaluation to all infants who screen positive for hearing loss before 3 months of age to confirm infant/child hearing loss, including type, configuration, and degree.	a. Number and percent of infants who screened positive and received a comprehensive audiologic evaluation before 3 months of age. b. Number and percent of infants with bilateral or unilateral hearing loss. c. Number and percent of infants with permanent conductive, sensorineural, or auditory dys-synchronous hearing loss. d. Number and percent of infants with mild, moderate, severe, moderately-severe, or profound hearing loss. e. Number and percent of infants referred for audiologic evaluation who were lost to follow-up. f. Number and percent of infants at risk of developing late onset hearing loss who were lost to follow-up.

	g. Number and percent of infants referred for audiologic evaluations who were not screened for hearing loss.
--	--

<p><i>2.2 Evaluation protocols.</i> Each state will develop and make accessible protocols and guidelines for appropriate diagnostic audiologic evaluation and recommendations for management (e.g., amplification, rehabilitation). These guidelines will be developed with input from state and local audiologists and based on current national guidelines.</p>	<ul style="list-style-type: none"> a. Documented list of acceptable measures to be included in the test battery for the identification of hearing loss and minimum frequency of evaluation to monitor the hearing sensitivity of all infants and children identified with hearing loss and all infants and children identified at risk for late onset, progressive, or acquired hearing loss. b. Copy of diagnostic management (e.g. amplification, rehabilitation) protocol that is based on current national guidelines (JCIH, ASHA, AAA). c. Documentation of availability of protocols for audiologists in a variety of formats.
<p><i>2.3 List of diagnostic audiologic providers.</i> Each state will maintain a current resource list of diagnostic centers and/or pediatric audiologists who have experience and expertise in administering diagnostic audiologic evaluations for infants, according to the protocol and guidelines.</p>	<ul style="list-style-type: none"> a. List of diagnostic centers and audiologists that have experience or expertise in conducting pediatric audiologic assessments. b. Number of centers and audiologists that have appropriate equipment for diagnostic evaluation of infants. c. Number of hospitals or referral personnel that maintain a list of diagnostic centers or audiologists.
<p><i>2.4 Linkage to appropriate follow-up.</i> Each state will identify a linkage system to ensure that families of infants identified with hearing loss will have appropriate referral to medical, audiologic, and intervention services, according to state resources.</p>	<ul style="list-style-type: none"> a. Number and percent of infants identified with hearing loss referred to medical specialists, such as otolaryngologists, ophthalmologists, and geneticists. b. Number and percent of infants with hearing loss who are referred to early intervention services, including counseling and support services. c. Number and percent of infants with hearing loss who are referred to ongoing audiologic evaluations and services.
<p><i>2.5 Education and training for audiologists.</i> Each state will develop an education/ training plan for audiologists to ensure competency in pediatric evaluation, management, and family counseling.</p>	<ul style="list-style-type: none"> a. Documented training plan for audiologists. b. Number of audiologists trained.
<p><i>2.6 Education and Training for other providers.</i> Each state will develop an education and training plan for primary care providers, public health nurses, and others on the importance and process of audiologic evaluation.</p>	<ul style="list-style-type: none"> a. Documented training plan for other providers. b. Number of professionals trained.
<p><i>2.7 Information on the audiologic evaluation process.</i> Parents and guardians will be informed in a culturally sensitive and language-appropriate manner about the diagnostic audiologic evaluation process and report.</p>	<ul style="list-style-type: none"> a. Documentation of language-appropriate materials and interpreter services to describe audiologic services and reports. b. Documented plans for disseminating materials. c. Number of materials distributed.

Goal 3. All infants identified with hearing loss will receive appropriate early intervention services before 6 months of age (medical, audiologic, and early intervention).

Program Objectives	Performance Indicators**
<p>3.1 <i>Medical services.</i> All infants identified with hearing loss will receive appropriate medical services, such as primary care, visual screening, genetic services, and counseling before 6 months of age.</p>	<p>a. Number and percent of infants with hearing loss who received appropriate medical services before 6 months of age from: primary care, otolaryngologists, ophthalmologists, and geneticists/genetic counselors.</p>
<p>3.2 <i>Early intervention services.</i> Each state will ensure that all infants and children with documented hearing loss will receive appropriate early intervention services from Part C or other state approved intervention services. Service coordination will be provided to eligible children.</p>	<p>a. Number and percent of infants with hearing loss who were enrolled in an intervention program before 6 months of age b. Number and percent of infants and children with hearing loss who received family support information about early intervention services. c. Number and percent of eligible infants and children categorized by hearing loss who have a signed IFSP or an equivalent intervention plan. d. Number and percent of infants who are lost to follow-up after identification. e. Number and percent of infants with hearing loss eligible for Part C services with mild hearing loss, moderate hearing loss; moderately-severe hearing loss, severe hearing loss, or profound hearing loss.</p>
<p>3.3 <i>Audiologic services.</i> All infants identified with hearing loss will receive appropriate audiologic services before 6 months of age.</p>	<p>a. Documentation that confirms that families of children with hearing loss received information on communication and amplification options. b. Documentation of plan for management of each infant's and child's assistive technology that includes, at a minimum, use of probe microphone measures and recommendations for frequency of evaluation. c. Documentation of protocols and guidelines for managing the aural habilitation or rehabilitation of each infant or child. d. Number and percent of infants fitted with personal amplification before 6 months of age.</p>

****Some states may need to differentiate between Part C eligible and non-eligible infants.**

<p>3.4 <i>Policy statement for stakeholders.</i> Each state will adopt and distribute as appropriate a policy regarding the rights of every family to choose the communication modes and methods that are most appropriate for their child.</p>	<p>a. Documentation of procedural safeguards regarding the rights of families when choosing a communication mode for their children.</p> <p>b. List of resources and contacts providing information about various communication options to enable families to make more informed decisions.</p> <p>c. Documented plans for distributing the resource list and procedural safeguards to families identified by the newborn hearing screening program.</p>
<p>3.5 <i>Resource guide.</i> All states will develop a comprehensive, family-friendly Resource Guide that will include: material from a variety of sources; a list of relevant web sites; a list of state contact people. The Guide will be available in print as well as on a web site and in major languages used in the state, pending available resources.</p>	<p>a. Number and percent of parents and guardians of infants who have a confirmed hearing loss that reached 6 months of age within the last calendar year that received a copy of the state resource guide.</p> <p>b. Documentation of resource guides in any language spoken by 5% or more of the population in that state.</p> <p>c. The state resource guide will include a list of questions for parents to ask in assessing the philosophy and practices of programs they consider for their child.</p>
<p>3.6 <i>Membership of IFSP or other intervention team.</i> All families who have a child with identified hearing loss should have an individual on their intervention team who has knowledge, experience, and expertise with the issues related to children who are deaf or hard of hearing.</p>	<p>a. Number and percent of intervention teams that include individuals with professional preparation and experience working with children with hearing loss.</p>
<p>3.7 <i>Education and training.</i> States will provide opportunities to Part C and other intervention services to receive training on specific issues related to deafness and hearing loss.</p>	<p>a. Documentation of implemented and planned training sessions for Part C or other intervention service providers.</p>
<p>3.8 <i>Quality intervention systems.</i> States shall make sure that high quality early intervention systems are available, including those that meet the needs of diverse populations and children with additional disabilities.</p>	<p>a. List of intervention services that describe available services for diverse populations.</p> <p>b. Documentation of services for children with hearing loss who also have other disabilities.</p>

<p>3.9 <i>Recommendations for early intervention providers.</i> States shall develop a set of recommendations for early intervention providers who work with children who are deaf or hard of hearing and their families that include:</p> <ul style="list-style-type: none"> -identification of objective sources of information for families to learn about communication options, -guidelines for monitoring the communication and social skill development of the child with hearing loss at 6-month intervals, -identification by each early intervention program of personnel within their staffs who are specialists in deaf and hard of hearing issues, -process for linking to family-to-family support within an early intervention system, -list of preschool program options that are particularly prepared to serve children who are deaf or hard of hearing, and inclusion of this information in the preparation of the family for transition at age 3 years. 	<ul style="list-style-type: none"> a. Documented distributions of a resource guide that presents balanced information on communication options. b. Documented test scores for communication and social skill development at 6-month intervals. c. Documentation of annual updated guidelines. d. Number and percent of families referred to and involved in parent-to-parent support program.
<p>3.10 <i>Parent participation.</i> Each state will ensure families of children with hearing loss have an opportunity to actively participate in the EHDI system.</p>	<ul style="list-style-type: none"> a. Number and percent of parents involved in their child's program planning, evaluation, or monitoring. b. Number and percent of parents on the EHDI Advisory Board.

Goal 4. All infants and children with late onset, progressive or acquired hearing loss will be identified at the earliest possible time.

Program Objectives	Performance Indicators
<p>4.1 <i>Risk factors:</i> Each hospital, audiologist and other providers, will identify infants with risk factors for hearing loss and transmit the information to state.</p>	<ul style="list-style-type: none"> a. Number and percent of infants with one or more risk factors.
<p>4.2 <i>Monitoring of at-risk infants.</i> Each state will have a mechanism in place to monitor the hearing status of infants at risk for late onset and progressive hearing loss.</p>	<ul style="list-style-type: none"> a. Number and percent of infants with risk factors who are re-screened by 6 months.
<p>4.3 <i>Acquired hearing loss.</i> Each state will have a mechanism in place to identify and provide follow-up services for infants and children with acquired hearing loss.</p>	<ul style="list-style-type: none"> a. Number and percent of infants and children identified with acquired hearing loss.

5. All infants with hearing loss will have a medical home as defined by the American Academy of Pediatrics.

Program Objectives	Performance Indicators
5.1 <i>Medical Home.</i> Each infant with a confirmed hearing loss will have an identified primary care provider before 3 months of age.	a. Number and percent of infant records that include name of the infant's primary care provider. b. Documentation that the results of the infant's audiologic evaluation were sent to their primary care provider.
5.2 <i>Collaboration with early intervention.</i> Each medical home will collaborate with the early intervention system and the family to develop a plan to connect families to advocacy groups, parent support networks, and parent-to-parent support.	a. Documentation in each family plan or IFSP of collaboration between the early intervention systems and the medical home.
5.3 <i>Unbiased information.</i> Each state will develop resources that can be shared with the medical homes and families to provide unbiased information.	a. Documentation that the Resource Guide describing unbiased information regarding early intervention strategies is provided to physicians and other primary care providers.
5.4 <i>Education.</i> In partnership with parents of children with hearing loss, states will develop a plan to provide education about the state EHDI program to medical homes.	a. Documentation of plan to provide information on the EHDI program to the Medical Home of each infant and child. b. Number and percent of each type of medical home (physician, midwife, etc.) that receives written information or attends a session about the EHDI Program, or both.
5.5 <i>Parental input.</i> Each state will have a mechanism for obtaining parent feedback and including parents in the process of development and evaluation processes for the medical home.	a. Number of parents participating in the development and evaluation of the medical home. b. Results of survey or other mechanism to obtain parent feedback
5.6 <i>Continuous care.</i> Each state will have a mechanism for identifying and tracking the infant's primary care provider at key intervals, regardless of insurance status.	a. Number and percent of infant records with updated documentation of who the primary care provider is at birth, initial diagnosis, enrollment in early intervention and at each IFSP contact.

Goal 6. Every state will have a complete EHDI Tracking and Surveillance System that will minimize loss to follow-up.

Program Objectives	Performance Indicators
6.1 <i>Comprehensive system.</i> Each state will have a computerized system that maintains current information on hearing screening for every infant, evaluation for all infants and children who do not pass the screening and interventions for every infant and child from birth through 5 years of age with hearing loss.	a. Written description of computerized system b. Printouts and reports of screening, evaluation, and intervention data.
6.2 <i>Policies and procedures.</i> Each state will have written policies and procedures regarding operation of the EHDI Tracking and Surveillance System.	a. Documentation of policies and procedures manual.
6.3 <i>Privacy and confidentiality.</i> Each state will develop policies, procedures, and informed consent requirements regarding privacy and confidentiality of data in the EHDI Tracking and Surveillance System.	a. Documentation of policy and procedures on informed consent requirements.
6.4 <i>Include all births.</i> Each state will ensure that all live births in the state are included in the state EHDI Tracking and Surveillance System by matching with the state's birth certificates registry as allowed by state policy.	a. Number of live-born infants. b. Number and percent of infants screened. c. Documentation of Number and percent of matches with vital records.
6.5 <i>Risk factors for hearing loss.</i> The state EHDI Tracking and Surveillance System will ascertain risk factors for hearing loss for every infant by linkage with other state data systems, such as hospital records, birth certificates, birth defects, metabolic screening, immunizations, etc.	a. Number and percent of infants with risk factors. b. Number and type of risk factors for each infant.
6.6 <i>Newborn hearing screening results.</i> The state EHDI Tracking and Surveillance System will capture all hearing screening results at birthing hospital within a week after discharge or transfer.	a. Report on number and percent of infants screened that includes results for each ear, technology used, and age at screening.

6.7 <i>Reporting mechanism for health care providers.</i> Each state will provide a mechanism for hospitals, audiologists and other health care providers to report hearing screening results, evaluations and interventions.	<p>a. Number of health care providers that have protocols for reporting hearing screening results, evaluations and interventions.</p> <p>b. Number of health care providers reporting hearing screening results to the state.</p>
6.8 <i>Identifying children who need screening and follow-up.</i> The state EHDI Tracking and Surveillance System will be able to identify, on a [weekly] basis, all infants and children who need initial hearing screening, repeat testing, evaluation, follow-up, or intervention.	<p>a. Number and percent of infants and children needing follow-up who:</p> <ul style="list-style-type: none"> -were referred for second screening -missed screening - need a repeat screening -were referred for diagnostics - were referred for early intervention <p>b. Number and percent of infants and children who received follow-up.</p>
6.9 <i>Access to information.</i> The state EHDI Tracking and Surveillance System will allow case managers and authorized health care providers to access relevant information about infants and children.	a. Written plan to allow case managers and authorized health-care providers to access relevant information.

Goal 7. Every state will have a comprehensive system that monitors and evaluates the progress towards the EHDI Goals and Objectives.

Program Objectives	Performance Indicators
7.1 <i>Advisory Committee.</i> Each state's advisory committee will meet routinely to provide guidance on the EHDI system. The committee should include professionals, individuals with hearing loss, families with children who have permanent hearing loss, and others to provide guidance on the development and evaluation of the EHDI system.	<p>a. List of Advisory Committee members.</p> <p>b. Minutes of Advisory Meetings</p>
7.2 <i>Monitoring and evaluation.</i> Each state EHDI program will develop a program evaluation plan in collaboration with the program Advisory Committee to ensure progress towards national and state program goals and objectives.	a. Annual evaluation reports that include accomplishments of national and state program goals and objectives.
7.3 <i>Feedback from families.</i> The state EHDI program will obtain feedback from parents on the EHDI process	<p>a. Copy of survey of parent concerns and issues.</p> <p>b. Documented results of parent survey to stakeholders.</p>

<p>7.4 <i>Surveillance of follow-up services.</i> Each state will ensure that infants and children with hearing loss receive ongoing and appropriate follow-up services.</p>	<ul style="list-style-type: none"> a. Number and percent of infants and children with hearing loss that received appropriate ongoing medical services from primary care, otolaryngologists, ophthalmologists, geneticists and genetic counselors. b. Number and age of infants and children fitted with implants. c. Number and percent of infants and children using each mode of communication, e.g., sign language, oral, cued speech at 6-month intervals. d. Number and percent of infants and children achieving communication and social skills scores commensurate with their cognitive abilities age at 1, 3, 5, and 7 years of age. e. Number and percent of infants and children with hearing aids that receive follow-up visits at 2-month intervals until age 2 years and 3-month intervals until age 3.
--	--

**Early Intervention for Deaf and
Hard of Hearing Children and their Families
Stakeholder's Meeting
March 28, 2006**

Examples of Program Vision Statements

Children's Special Health Care Services

CSHCS strives to enable individuals with special health care needs to have improved health outcomes and an enhanced quality of life through the appropriate use of the CSHCS system of care.

Our goals are to:

- ◆ Assist individuals with special health care needs in accessing the broadest possible range of appropriate medical care, health education and supports.
- ◆ Assure delivery of these services and supports in an accessible, family-centered, culturally competent, community-based and coordinated manner.
- ◆ Promote and incorporate parent/professional collaboration in all aspects of the program.
- ◆ Remove barriers that prevent individuals with special health care needs from achieving these goals.

Early On Vision Statement

Michigan will respect the uniqueness of children ages birth through five with special needs and their families through an outcome based, developmental, natural support delivery system.

The Great Start System

Vision

A Great Start to make every child in Michigan safe, healthy, and eager to succeed in school and in life.

Mission

The purpose of Great Start is to assure a coordinated system of community resources and supports to help all Michigan families provide a great start for their children from birth to age five.

Center for Disease Control

The vision of the Center for Disease Control and Prevention's (CDC) Early Hearing Detection and Intervention (EHDI) program is to promote communication from birth for all children.

Our Mission

The mission of CDC EHDI programs is for every state and territory to have a complete EHDI tracking and surveillance system that ensures children with hearing loss achieve communication and social skills commensurate with their cognitive abilities. To do this, it is essential that infants with hearing loss are identified early, and appropriate intervention services are initiated. Without early identification and intervention, children with hearing loss may experience delays in the development of language, cognitive, and social skills that may prevent success in academic and occupational achievement.

Our Goals

CDC and state representatives developed seven national goals that illustrate the comprehensiveness of EHDI programs, and reflect the ideal achievement. For each national goal there is a set of specific program objectives, that are essential in accomplishing each national goal. Each program objective has a quantitative measure (performance indicator) that can be used to track the progress toward the goals and objectives.

Maternal and Child Health Bureau

Vision

A future America in which the right to grow to one's full potential is universally assured through attention to the comprehensive physical, psychological and social needs of the maternal and child health population. We strive for a society where children are wanted and born with optimal health, receive quality care and are nurtured lovingly and sensitively as they mature into healthy, productive adults. MCHB seeks a nation where there is equal access for all to quality health care in a supportive, culturally competent, family and community setting.

Mission Statement

The mission of the Maternal and Child Health Bureau (MCHB) is to provide national leadership, in partnership with key stakeholders, to improve the physical and mental health, safety and well-being of the maternal and child health (MCH) population which includes all of the nation's women, infants, children, adolescents, and their families, including fathers and children with special health care needs.

Goals

Goal 1: Provide National Leadership for Maternal and Child Health

Goal 2: Promote an Environment that Supports Maternal and Child Health

Goal 3: Eliminate Health Barriers and Disparities

Goal 4: Improve the Health Infrastructure and Systems of Care

Goal 5: Assure Quality of Care

Colorado Home Intervention Program Vision Statement

The mission of the **Colorado Home Intervention Program** is to provide services to families and their very young children who are deaf or hard of hearing. Professionals and family members form a partnership to support the development of the child; providing education to family members, teaching family members specific techniques to support their child's learning, and providing children with a strong foundation to assure they have every opportunity to develop communication and language skills that correspond to their hearing peers. This mission is achieved through home-based, family-centered, evidence-based early intervention services.

**Early Intervention for Deaf and
Hard of Hearing Children and their Families
Stakeholder's Meeting
March 28, 2006**

Proposed Vision Statement

Every family with a Deaf and/or Hard of Hearing child should have access to high quality services for both the parents and the child that help the child to achieve language, cognitive, and social skills to be safe, healthy, and eager to succeed in school and in life.

Our goals are:

- Newborn Hearing Screening by 1 month of age.
- Audiologic Diagnostic Evaluation by 3 months of age.
- Intervention by 6 months of age which includes coordination and implementation of educational, health care services and related programs centered around family choice and family-centered care

1) What is **good** about this vision statement?

2) What could be **better** about this vision statement?

3) What would you make totally **different** about this vision statement?

Beyond Newborn Hearing Screening

2004 Consensus Conference on Effective
Educational and Health Care Interventions:
Infants and Young Children with Hearing Loss

(Marge & Marge)



A Call to Action...

*... a glimmer of hope that, at last, we may realize
a dream of long ago – that infants and young children
with hearing loss will receive the best possible services
in a timely, facile, and cost-effective manner so that
they may reach their full potential*



Elements of a Model Educational Program

1. Effective Child Find efforts
2. Key decision-making by the *family* about *choice of services* among *all options*
3. *Choice of services* that are specific to the needs and capabilities of the child and family
4. Ongoing *monitoring of outcomes* serves as a basis for educational planning
5. Certified and qualified service providers with *expertise* in working with infants and young children who are D/HH
6. Financial support to all children with hearing loss



Recommendations for a Model Program for Health Care Interventions

- ❑ Seamless system of service delivery initiated at the time of the child's failure of the neonatal screening
- ❑ Approaches should be accessible, family-centered, comprehensive, continuous, coordinated, compassionate, culturally sensitive
- ❑ Approaches include ongoing surveillance
- ❑ Approaches encourage parental empowerment
- ❑ Appropriate amplification technology should be selected after evaluation and verification
- ❑ Specialty referrals for children identified with hearing loss to otolaryngology, genetics, ophthalmology, and others as needed




Recommendations for Implementing Effective Health Care Interventions

- ❑ Increase the number of audiologists who have the training, experience, and resources availability and are capable of providing quality audiologic services to infants and young children
- ❑ Increase public awareness and knowledge about childhood hearing loss including genetics, progression, late onset hearing loss, impact of COM
- ❑ In order to provide coordinated and appropriate services in a timely manner, all states must have longitudinal tracking and surveillance systems
- ❑ Innovative models to serve rural and other under-served populations



Recommendations for a Model Educational Intervention Program


1. Family involvement has a significant impact on a child's progress and therefore a *family-centered approach* should be used for infants and young children with hearing loss
2. Choice of communication approach and language system and educational setting is a *process* that requires *collaboration* between parents and *specifically-trained* professionals
3. Provide proactive, comprehensive and ongoing audiologic management, both for the hearing loss and the applied technology (e.g., Hearing Aid Loaner Bank)


- 
-
4. Develop guidelines for increasing or decreasing placement in mainstream education settings based on the child's communication and academic development (e.g., parent-to-parent support, D/HH role models, consultative services)
 5. The specialized and technological needs of infants and children with hearing loss are unique and require a professional with specific training in providing services for these children
 6. Continually update and improve curriculum and training resources and materials for serving infants and young children with hearing loss and their families based on *research evidence*



Specific Recommendations for Combining Educational and Health Care Services

1. A *single point of entry* into a comprehensive, coordinated and continuous system of services
2. Coordination of resources among agencies (e.g., PCP coordinates with the child's case manager)
3. Each state should identify or establish Centers of Excellence and/or Networks of Expertise to facilitate collaboration and coordination of optimal care that includes *professional training, technical assistance* and dissemination of information
4. Children with *all types of hearing loss* should be eligible for services

- 
-
5. The case coordinator must be sensitive to the needs of parents who are Deaf whose newborn or young child has a hearing loss
 6. Parents from *minority cultures*, particularly those whose primary language is not English, should be provided with resources that helps them overcome difficulties coping with and successfully navigating through the necessary interventions

- 
-
7. Early interventionists and health care providers become knowledgeable about the *different models of the deaf experience*
 - i. Deafness as a medical condition
 - ii. Deafness as a life experience and/or cultural community
 8. Provide appropriate support for families (includes a parent resource center) specific for parents of children with hearing loss
 9. Ensure services to all who need it
 10. Provide training to early intervention staff so that *information bias is reduced*

**Early Intervention for Deaf and
Hard of Hearing Children and their Families
Stakeholder's Meeting
March 28, 2006**

**Attributes of a Model System of Care
for Deaf and Hard of Hearing Infants and Young Children**

Add transitional statements
Discuss funding issues
Combine all categories into one system
Weave evaluation throughout the entire system
Personal planning strategies

Educational

1. More information to parents for decision making process – mentors, exposure to options
2. Effective and sustainable child find efforts
3. Parents desired outcome for their child needs to be identified and respected
4. Parents are equal partners – home service providers versus parents/professionals
5. Communication: between family members and between family and providers
6. Key Decision making by the family about choice of services among all options
7. Choices of services that is specific to the needs and capabilities of the child and family
(parents need exposure to communication choices to make informed decisions)
8. Ongoing monitoring of outcomes serves as a basis for educational planning
9. Certified and qualified service providers with expertise in working with infants and young children who are deaf or hard of hearing.
10. Financial support to all children with hearing loss
11. Develop language plan

Health Care

1. Communication: between family members and between family and providers
2. Effective and sustainable child find efforts
3. Parents desired outcome for their child needs to be identified and respected
4. Parents are equal partners – home service providers versus parents/professionals
5. Technical expertise and access to factual information to the families and PCP

6. Seamless system of service delivery initiated at the time of the child's failure of the neonatal screening or identification of high-risk indicators for late onset or progressive hearing loss, or the identification of hearing loss in childhood.
7. Medical home identified as the primary care physician
8. Medical communication assure parents have information regarding all options
9. Financial support to all children with hearing loss
10. Family counseling for hearing or deaf parents to help them accept their hard of hearing or deaf child.
11. Specialty referrals for children identified with hearing loss to otolaryngology, genetics, ophthalmology, and others as needed
12. Monitoring of outcomes serves as a basis for service planning

Coordination of Educational, Health Care Services and Programs

1. Single point of entry and family access to key individuals at the beginning to ensure uniform information provision and easy transition from diagnostic audiology to intervention
2. General education and awareness of the (perhaps something is missing here) community (define community) **and its resources.** Facilitator/coordinator
3. Family- and child-centered (deaf and hard of hearing role models for the child – and the family – combined) (define child-centered) perspective should provide the framework for newborn hearing screening, evaluation, and early intervention programming
4. Coordination of resources across agencies
5. Parents are equal partners – home service providers versus parents/professionals
6. Centers of excellence
7. Establishment of joint system outcomes
8. Integrated data system including data sharing and a communication policy (define policy and communication) Communication between agencies (HIPPA, FERPA, accountability system, policies in place that are barriers to communication)